



## Frequently Asked Questions about Lupus

### What is systemic lupus erythematosus (SLE) or lupus?

SLE, usually referred to as lupus, is an *autoimmune* disease. Autoimmune diseases are illnesses in which the immune system becomes overactive and attacks healthy body tissue. This tendency for the immune system to become overactive seems to run in families. Other factors, such as exposure to infections or other environmental triggers, are also thought to be involved. Lupus affects many more women than men, and black women more than white women.

Lupus can affect the joints, skin, kidneys, heart, lungs, blood vessels, and brain, causing inflammation and damage. For most people, lupus is a mild disease affecting only a few organs. For others, it can be disabling and cause serious and even life-threatening problems. One in five people with the disease are disabled, most commonly from fatigue and joint and muscle pain. Fifteen to 20 percent of all cases of lupus result in death, often from kidney disease, infection, and *cardiovascular disease*.

Currently, there is no cure for lupus. However, with early diagnosis and treatment, symptoms can usually be managed. Most people with the disease can lead active, healthy lives.

### Who has lupus?

Surveys have shown that lupus affects up to 2 million people in the United States. About 9 out of 10 people who have lupus are women. Lupus is three times more common in black women than in white women. It is also more common in women of Hispanic, Asian, and Native American descent. Researchers are trying to learn why these women are more likely to get lupus.

The disease often starts between the ages of 15 and 44. In some people, lupus becomes active after exposure to sunlight, infections, or certain medicines.

### What are the different kinds of lupus?

There are several forms of lupus:

- *Systemic lupus erythematosus* (SLE) is the form of the disease that most people are referring to when they say "lupus." SLE can affect many parts of the body including joints, skin, kidney, lungs, heart and brain. Its symptoms can range from mild to serious. Although SLE usually develops in people between the ages of 15 and 44 years, it can occur in childhood or later in life as well.
- *Discoid lupus erythematosus* (DLE) mainly affects the skin. It causes a red, raised rash on the face, scalp, or other parts of the body. The rash may become thick and scaly and may last for days or years. A small percentage of people with DLE later develop SLE.
- *Drug-induced lupus* is a rare reaction to some prescription medicines. It resembles SLE, but is less serious. Symptoms go away when the drug is stopped.

- *Neonatal lupus* can affect some newborn babies of women with SLE or certain other immune system disorders. Babies with neonatal lupus may have a serious heart defect. Other affected babies may have a skin rash, liver problems, or low blood counts. Neonatal lupus is very rare, and most infants of mothers with SLE are healthy.

## What are the signs of lupus?

The signs of lupus vary and there are usually periods of both illness called and wellness (remission). Some people have just a few signs of the disease while others have more. Many people with lupus look healthy. Lupus may be hard to diagnose and is often mistaken for other diseases. For this reason, lupus has often been called the "great imitator."

The following are some common signs and symptoms of lupus:

- Extreme fatigue
- Painful or swollen joints (arthritis)
- Unexplained fever
- "Butterfly" rash across the nose and cheeks that is typical of lupus
- Skin rashes on other parts of the body
- Chest pain or pleurisy (inflammation of the *pleura*, the membrane that covers the lungs)
- Unusual loss of hair
- Pale or purple fingers from cold or stress
- Sensitivity to the sun
- Low red blood-cell count
- Seizures
- Mouth or nose ulcers

These signs are more important when they occur together. Some people also experience headaches, dizziness, or depression. Some women have repeated miscarriages. New symptoms may continue to appear years after the initial diagnosis, and different symptoms can occur at different times.

## What causes lupus?

Lupus is a complex disease whose cause is unknown. It is likely that there is no single cause but rather a combination of genetic, environmental, and possibly hormonal factors that work together to cause the disease. The exact cause may differ from one person to another. No specific "lupus gene" has been identified. Instead, it appears that several inherited genes may make a person more susceptible to the disease.

## Does sunlight cause lupus?

Being out in the sunlight can trigger signs and symptoms of lupus. *Photosensitivity* is an abnormal reaction to the ultraviolet (UV) rays of the sun. About a third of persons with lupus are photosensitive. In these persons, sun exposure can cause or worsen a rash, and can sometimes cause other symptoms. People with lupus should avoid direct, prolonged exposure to the sun.

If you are sensitive to the sun, you should:

- Frequently apply a sunscreen with a Sun Protection Factor (SPF) of at least 15
- Avoid unprotected exposure between 10 a.m. and 4 p.m.
- Wear protective clothing, such as wide-brimmed hats and long sleeves.

Keep in mind that UV rays are reflected off water and snow. Also, glass (such as car windows) does not provide total protection from UV rays. Fluorescent and halogen indoor lights can emit UV rays that can aggravate lupus. If you work in an office lit by these kinds of lights, there are plastic devices that can block UV emissions from them.

## Why is lupus more common in black women than in white women?

We do not know why the disease is more common in black women. However, researchers are studying why minorities are more inclined to get lupus, what causes it to start, and why it is mild in some and severe in others. Other researchers are studying why the signs of lupus differ between black women and white women.

## How is lupus diagnosed?

Early diagnosis and treatment are needed to improve health and reduce tissue damage. Diagnosing lupus can be difficult, however. It may take months or even years for doctors to piece together the symptoms to make an accurate diagnosis. Giving the doctor a complete, accurate medical history is very important. This information, along with a physical exam and the results of tests, helps the doctor rule out other diseases that may mimic lupus. Reaching a diagnosis may take time and occur gradually as new symptoms appear.

No single test can determine whether a person has lupus. The *antinuclear antibody (ANA)* test is a commonly used test. Most people with lupus test positive for ANA; however, there are a number of other causes of a positive ANA. In addition, there are blood tests for individual types of antibodies that are more specific to people with lupus, although not all people with lupus test positive for these and not all people with these antibodies have lupus.

Other tests are used to monitor the progress of the disease once it has been diagnosed. A complete blood count, urinalysis, blood chemistries, and *erythrocyte sedimentation rate (ESR)* test can provide valuable information. Another common test measures the blood level of a group of substances called *complement*. People with lupus often have increased ESRs and low complement levels, especially during flares of the disease.

## How is lupus treated?

Because the signs of lupus often differ from one person to another, treatment varies. There is no known cure today for lupus. However, in many cases, symptoms of the disease can be relieved. The good news is that with the correct medicine and by taking care of themselves, most persons with lupus can hold jobs, have children, and lead full lives.

Once lupus has been diagnosed, the doctor will develop a treatment plan. The plan is based on the person's age, gender, health, symptoms, and lifestyle. Tailored to the person's needs, this plan may change over time. Treatment is used to prevent flares, to effectively treat them when they do occur, and to reduce complications.

Treatment may include:

- Aspirin or similar medicine to treat the painful, swollen joints and the fever
- Creams to treat the rash
- Stronger medicines for more serious problems, based on the person's individual symptoms and needs
- Physical and emotional rest
- Protection from direct sunlight
- A healthful diet and exercise
- Prompt treatment of infections
- Avoidance of known *allergens* and aggravating factors

Drugs used in treating lupus include:

- **Nonsteroidal anti-inflammatory drugs (NSAIDs).** NSAIDs are often used to reduce pain and inflammation in persons who have mild SLE. There are many different types of NSAIDs, both prescription drugs and over-the-counter drugs. They include aspirin, ibuprofen, naproxen, and other medicines. Common side effects of NSAIDs can include stomach upset, heartburn, diarrhea, and fluid retention. Some persons with lupus also develop liver and kidney inflammation while taking NSAIDs, making it especially important to stay in close contact with your health care provider while taking these medications.
- **Antimalarial drugs.** These drugs were originally used to treat malaria, but doctors have found that they also are useful for lupus. They may work by suppressing parts of the immune response. They may be used alone or in combination with other drugs to treat fatigue, joint pain, skin rashes, and inflammation of the lungs.

Two common antimalarials used to treat lupus are *hydroxychloroquine* (Plaquenil) and *chloroquine* (Aralen). Side effects of antimalarials can include stomach upset, nausea, vomiting, loss of appetite and, in rare cases, damage to the retina of the eye.

- **Corticosteroid hormones.** These are powerful drugs that reduce inflammation in various tissues of the body. They can be given by mouth, in creams applied to the skin, or by injection. Prednisone is a corticosteroid that is often used to treat lupus. These drugs have various side effects, so doctors try to use the lowest dose possible. Short-term side effects of corticosteroids include swelling, increased appetite, weight gain, and emotional ups and downs. These side effects generally stop when the drug is stopped. Long-term side effects of corticosteroids can include stretch marks on the skin, excessive hair growth, weakened or damaged bones, high blood pressure, damage to the arteries, high blood sugar, infections, and cataracts.

People with lupus who are using corticosteroids should talk to their doctors about taking calcium supplements and vitamin D or other drugs to reduce the risk of *osteoporosis* (weakened, fragile bones).

**Immunosuppressive agents.** These drugs suppress the immune system. Examples are *azathioprine* (Imuran) and *cyclophosphamide* (Cytoxan). They are used in serious cases of lupus, such as in cases when major organs like the kidneys are affected. These drugs can cause serious side effects including nausea, vomiting, hair loss, bladder problems, decreased fertility, and increased risk of cancer and infection.

New drug treatments are being tested, including hormonal treatments. Working closely with the doctor helps ensure that treatments for lupus are as successful as possible. Because some treatments may cause harmful side effects, it is important to promptly report any new symptoms to the doctor.

It is also important not to stop or change treatments without talking to the doctor first. With early diagnosis and the correct treatment and medication, most people with lupus can maintain an overall high quality of life.

## **I am pregnant. Will my lupus affect my baby?**

Although a lupus pregnancy is considered high risk, most women with lupus carry their babies safely to the end of their pregnancy. Women with lupus are more likely to have a miscarriage than other women. Although experts disagree on the exact numbers, approximately 20 to 25 percent of lupus pregnancies end in miscarriage, compared to 10 to 15 percent of pregnancies in women without the disease. About one in four babies of women with lupus are born prematurely.

Pregnancy counseling and planning before pregnancy are important. Ideally, a woman should have no signs or symptoms of lupus and be taking no medicines for at least 6 months before she becomes pregnant.

Some women may experience a mild to moderate flare during or after their pregnancy; others do not. Regular care and good nutrition during pregnancy are essential.

## **How can I cope with the stress of having lupus?**

Staying healthy takes extra effort and care for people with lupus. You must cope with the stress of having a chronic disorder. Some approaches that may help include:

- Exercise
- Relaxation techniques such as meditation
- Setting priorities for spending time and energy
- Educating yourself about the disease
- Having a good support system.

A support system may include family, friends, health care providers, community organizations, and organized support groups. Participating in a support group can provide emotional help, boost self-esteem and morale, and help develop or improve coping skills. It is important to follow up with your health care provider(s) on a regular basis, even when your lupus is quiet and all seems well.

## **What research is being done on lupus?**

Promising areas of research on treatment for lupus include biologic agents; newer, more selective drugs that suppress the immune system; and bone transplants to correct immune abnormalities.



## **For more information...**

For more information on lupus, call the National Women's Health Information Center (NWHIC) at 800-994-WOMAN or contact the following organizations.

### **National Library of Medicine's MEDLINEplus**

Phone Number(s): (888) 346-3656

Internet Address: <http://www.nlm.nih.gov/medlineplus/lupus.html>

### **National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**

Phone Number(s): (301) 496-4484

Internet Address: <http://www.niams.nih.gov>

### **National Institute of Allergy and Infectious Diseases**

Phone Number(s): (301) 480-2814

Internet Address: <http://www.niaid.nih.gov/publications/autoimmune/default.htm>

### **National Institutes of Health (NIH) Office of Research on Minority Health**

Minority Health Initiative—Lupus Erythematosus

Phone Number(s): (301) 402-1366

Internet Address: <http://www1.od.nih.gov/ORMH/mhi/research/lupus.html>

### **American Autoimmune Related Diseases Association, Inc.**

Phone Number(s): (810) 776-3900 or (800) 598-4668 Literature Requests

Internet Address: <http://www.aarda.org/index.html>

### **Lupus Foundation of America**

Phone Number(s): (800) 558-0121

Internet Address: <http://www.lupus.org/>

### **American College of Rheumatology**

Phone Number(s): (404) 633-3777

Internet Address: [www.rheumatology.org](http://www.rheumatology.org)

This information was abstracted from fact sheets prepared by the National Institute of Arthritis and Musculoskeletal and Skin Diseases.

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*August 2002*